

## In search of a good death

### Doctors need to know when and how to say die

EDITOR—One of the main obstacles to the care of dying patients is the taboo against speaking or writing about impending death. Here are a few simple tests to see how you or your colleagues are doing.

Try reading a selection of charts of patients who have died. Patients do “poorly,” “fail to respond,” or are “palliative,” but I would wager that you will find few patients described as “dying” or “near death.” Some dying patients even “demand” futile treatment such as cardiopulmonary resuscitation in the event of a “cardiopulmonary arrest,” when asked to “consent” not to receive it.

You should also see how often and how vigorously you avoid talking about death when speaking to a patient likely to die. I am always surprised at how difficult I find it to talk openly about death and dying, even when it clearly is necessary and appropriate and I have carefully thought out what I am going to say.

If compassionate care of dying patients is to occur doctors need a structured and consistent approach to talking with patients about death and dying.

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### Humanising effects of a good death will help society

EDITOR—As part of our work to support the British government's recent fundamental review of death certification we interviewed doctors about its processes and practice.<sup>1</sup> We found that doctors often approached death certification as an interruption of their real work, describing the completion of a death certificate as an irritation or a necessary evil.

Research in the United Kingdom and elsewhere suggests that death certificates are not completed accurately, which is not surprising given these views. However, death certificates are important. They are used to construct meaning for relatives and, equally importantly, to construct mortality data. Mortality data inform health policy and flows of healthcare resources. Death certificates thus ensure the production of accurate health statistics, a fact rarely appreciated by doctors who complete them.

Would-be doctors and health specialists should perhaps be taught that serious and terminal illnesses are part of a single process that may lead to dying and eventually death. Dying and death are part of the real work of health care, and the best care of living people often entails acknowledging the possibility of death. Incorporating ideas and attitudes about a good death into the curriculum will have many benefits, not least that doctors would be less likely to believe that death certificates were a necessary evil.

Completing an accurate death certificate may be one of the last acts of good medical care a doctor can perform for his or her patient. It can allow the relatives and friends to understand more clearly what has happened to the person who has died, as well as allowing the best use to be made of that person's death to improve the health of the living. The more accurate a society's mortality statistics the better informed it is to deliver the best health care to its living members.

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<sup>1</sup> *Death certification and investigation in England, Wales and Northern Ireland*. Norwich: Stationery Office, 2003. (CM 5831.)

## Medical education has important role in extending palliative care

EDITOR—Death is still society's final taboo, as the article by Ellershaw and Ward showed.<sup>1</sup> All medical schools in the United Kingdom now include some teaching on palliative care in their undergraduate curriculum, but most of the emphasis has been on the care of patients dying of advanced cancer. Much palliative care teaching continues to be didactic and formal assessment is rare.<sup>2</sup>

Despite almost all students being taught palliative care within undergraduate training, house officers struggle more with this aspect of work than almost any other during their first years on the wards and are frustrated by their lack of skills and knowledge when caring for a patient who is dying. Many patients and families find the provision of palliative care delivered in an effective yet caring manner falls far short of their expectations.<sup>3</sup>

Nurses at all levels also have a crucial role in providing and delivering palliative care. They spend their immediate postregistration period in hospitals where they will encounter many patients with palliative care needs. A recent paper showed that undergraduate nursing students receive a mean of 12.2 hours of teaching in palliative care, compared with a mean of 20 hours' teaching offered to undergraduate medical students in the United Kingdom.<sup>4</sup> The teaching delivered to undergraduate nurses was mainly theoretical and rarely formally assessed. Tutors identified the lack of suitably skilled staff to teach palliative care and the shortage of placements for nursing students within a palliative care setting as particular difficulties.

The key to providing effective palliative care for all has to be the provision of a generic evaluated and assessed core undergraduate curriculum for medical and nursing undergraduates coupled with appropriate postgraduate and continuing professional education, but it is also important to remember that the way this care is delivered has longstanding effects on patients and their families.

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*The Apparition* by Gustave Moreau (1826-98)

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**A good death is an oxymoron without consideration of mental health**

EDITOR—Ellershaw and Ward are to be commended for their useful review of “evidence-based guidelines on symptom control, psychological support, and bereavement ... to facilitate a ‘good death.’”<sup>1</sup> Their recommendations for diagnosing dying are concrete, thorough, and practical.

By contrast, they write only two sentences about the provision of psychological care: “Patients’ insight into their condition should be assessed. Issues relating to dying and death should be explored appropriately and sensitively.” Both statements relate to the patient’s understanding of, and reactions to, being terminally ill; neither relates to an assessment of the patient’s psychological symptoms or disorders—for example, depressive and anxiety related symptoms and disorders—or to ways to treat mental illness when it is present. The under-recognition and undertreatment of psychic distress in dying patients prove unfortunate omissions in terminal care for several reasons.

Firstly, psychiatric disturbances are highly prevalent—for example, an estimated 20-50% of terminally ill patients meet established criteria for depression.<sup>2</sup>

Secondly, it is almost axiomatic to state that mental illness diminishes a patient’s quality of life at the end of life, thereby compromising an ability to achieve a good death.

Thirdly, psychiatric disorders can be diagnosed reliably within minutes, and effective, non-contra-indicated treatment is readily available.<sup>3-5</sup> Thus, with little additional burden to the healthcare system, the quality of life of dying patients could be vastly improved by detecting and treating their psychiatric problems.

Recommendations for a good death miss a critical aspect of wellbeing and care if they ignore the mental health of dying patients. If they are truly interested in promoting a good death, doctors need to overcome a prejudice against attending to mental, in contrast with physical, illness in patients who are terminally ill.

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**Health professionals’ beliefs may undermine effective pain relief for dying patients**

EDITOR—Murray et al include pain relief for dying people among the essential health interventions that should be accessible for all, in developing countries.<sup>1</sup> Even developed countries, however, have different pain relief policies.

In Italy, where medicinal morphine consumption for 2000 ranked among the lowest in Europe,<sup>2</sup> a restrictive prescription law was held responsible for the undertreatment of pain. The law was modified but with little effect.<sup>3,4</sup>

The results of a large survey of neonatal physicians and nurses in seven Western European countries (EURONIC) shed some light on additional factors undermining effective pain control in palliative care.<sup>5</sup> When asked about acceptable ways of setting limits to intensive interventions felt to be no longer in the best interest of a baby, most respondents in every country but Italy judged the administration of drugs to control pain to be morally acceptable “even if this might cause respiratory depression and death” (table).

In multivariate analysis other factors in addition to country and professional role were significantly associated with a positive view of analgesia for dying babies. These were having between 6 and 10 years of experience in neonatal care, as opposed to being junior or older (odds ratio 1.30, 95% confidence interval 1.00 to 1.70); being a parent (1.40, 1.11 to 1.77); and being routinely involved in research (1.46, 1.02 to 2.08). In contrast, religiousness (defined as considering religion very or fairly important in one’s life) decreased the likelihood of viewing this form of analgesia as morally acceptable (0.54, 0.45 to 0.65).

Percentages (95% confidence intervals) of respondents who thought that giving drugs to control pain is acceptable in palliative care “even if this might cause respiratory depression and death”

Country	Doctors (n=1207)	Nurses (n=3008)
Italy	64 (56 to 71)	49 (40 to 57)
Spain	87 (81 to 91)	83 (79 to 87)
France	96 (91 to 98)	89 (86 to 92)
Germany	86 (78 to 91)	76 (71 to 81)
Netherlands	98 (89 to 100)	92 (90 to 94)
United Kingdom	93 (89 to 96)	88 (84 to 92)
Sweden	95 (88 to 98)	90 (84 to 93)



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In Tlingit culture, Land-Otter-Man rescues the souls of drowning people and turns them into land otters

Fear of euthanasia, the health professional’s beliefs and prejudices, and lack of knowledge may represent obstacles to effective pain management for dying patients in countries where lack of resources for drugs is not an issue. Together with modification of the law, more education is needed in Italy to overcome the existing prejudices against the use of analgesia in palliative care.

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**Can children with life threatening illness and their families experience a good death?**

EDITOR—As care givers of children who are dying, we were disappointed that the experience of dying children and their families was not broached by Ellershaw and Ward or Clarke.<sup>1,2</sup> Do we in society continue to find it impossible to think about death in childhood? To imagine that children with life threatening illness and their families can experience a good death? What could possibly be experienced as good during this dying journey?

Paediatric palliative and hospice care continues to lack a significant voice in medi-

cal debates, literature, and research, as well as in the design and delivery of services. Why, for example, is there currently only one active free standing children's hospice in North America? Yet a significant number of children die of a life threatening illness or injury each year. In a population of 250 000 (50 000 children) five children are likely to die each year from a life threatening illness, including cancer and heart disease, and another 50 are likely to be living with a life threatening illness.<sup>3</sup>

We know from our clinical experience, from the honour of being with dying children and their families, that a good death is possible. We here list some elements that may contribute to a good death.

- An openness and willingness to engage in conversations between healthcare teams, children, and families about all options for care, including active treatment, palliative care, and their combination
- An equal understanding of and attention to physical, psychosocial, and spiritual needs regardless of the care setting (home, hospital, or hospice)
- The right of children and families to choose their care setting and move freely between settings as needed
- The right of children and families to choose whom they wish to be present at the time of death
- Care that is consistent, compassionate, culturally sensitive, and coordinated
- Care that is continuous through illness, dying, and bereavement

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### Palliative care is also remit of intensivists

EDITOR—Ellershaw and Ward reviewed the care of dying patients.<sup>1</sup> Children cared for in paediatric hospitals are given specialised, curative care appropriate for their develop-

mental level and range of acuity, but the importance of palliative care has been overlooked.<sup>2</sup> Doctors adept in pharmacotherapy should manage end of life situations in a manner that is sensitive to the needs of patients and care givers.<sup>3</sup>

Our paediatric critical care unit is a tertiary service with over 1200 admissions yearly. We care for children with a wide range of diagnoses, including traumatic injury, sepsis, respiratory failure, cancer, congenital heart disease, and genetic anomalies. Our service is often left with managing a life ending event or with planning and implementing a palliative care plan before discharge.

The death of a child is an emotive event for the family and a challenging time for the clinician.<sup>4</sup> We work closely with the palliative care service in caring for children with terminal conditions. This multidisciplinary team includes the hospital bioethics committee, clinical social workers, child life specialists, chaplains, primary nursing teams, subspecialty doctors experienced in terminal care, and the community doctor. We try to identify an appropriate place for dying in hospital or at home. Working with home health nurses, we are able to make the transition to home easy for the patient and family. End of life with experienced care givers is surely a standard we should all strive for.

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### Primary healthcare teams work in new framework for better care of the dying at home

EDITOR—Improving the care of the dying in the community is a crucial if neglected area of care, with a significant and far reaching impact. As the Audit Commission's report confirms,<sup>1</sup> too many people are staying too long in hospitals and better community palliative care could prevent inappropriate admissions, reducing hospital pressures and enabling more people to die at home. Ellershaw and Ward point to the improvements made in the recognition of dying and emphasise that a key aim of specialist palliative care is to disseminate this approach to generic healthcare workers in hospitals and in the community.<sup>2</sup>

Primary healthcare teams believe that palliative care is an important part of their work, and are keen to make improvements if enabled to do so. One means to optimise

community palliative care, suggested in the draft supportive care guidelines, is the Gold Standards Framework, a seven point plan to improve the organisation of the care for dying people, beginning with cancer patients but extending later to all dying patients.<sup>3</sup>

With detailed descriptions of the key issues and suggested measures to address these, this simple framework is beginning to have an impact on patient care, improving communication and proactive planning, enabling more to die where they choose, and raising awareness of patients' needs while also improving the sense of teamwork and morale of healthcare staff. It is already being used by over 500 general practices, including, for example, a third of all practices in Northern Ireland with a successful bid to offer this to every practice in Scotland.

The Macmillan Gold Standards Framework programme, supported by the Cancer Services Collaborative of the NHS Modernisation Agency, provides resources and support for locally facilitated practice teams. As Neuberger points out,<sup>2</sup> superb care and a good death at home are possible, and are made more likely by such a framework.

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### Good death is social construction

EDITOR—I refer to assumptions about the good death that are implicit in Ellershaw and Ward's paper.<sup>1</sup> Dying is a social process guided by expectations of appropriate behaviours which delimit a range of dying trajectories, thus defining normal and abnormal dying.<sup>2</sup>

One example of a good death discourse is dominated by a secular, autonomy driven, privacy oriented approach. It is promulgated in talk shows, the popular media, legislative chambers, and in societies devoted to a "dignified death," assistance in dying, or some euphemism for terminating human life in the name of compassion. Compassion, dignity, and freedom are also in biblical teachings, but they are different in spirit and content from the secular construal of those sentiments. The rules of discourse are now set so that any argument based on faith is inadmissible simply by virtue of its being religious.

If some hospices are finding it increasingly difficult to practise what they preached for years, what hope is there for an NHS stuck in a swamp of tick box rationality? We live in an era where prescriptive dictums reign supreme, producing an attentive work-



Sir Thomas Aston at the Deathbed of his Wife by John Souch, 1635

force who can recite, verbatim, procedure and protocol.

I am seriously concerned that “real time” care, never mind “good death” is being insidiously superseded by paranoid paperwork propagators who are sucking individuality from healthcare practice. Yes, we are encouraged to think freely by those who freely think on our behalf.

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### What is a good death?

EDITOR—Ellershaw and Ward describe how access to good palliative care should be available to all patients who are dying.<sup>1</sup> We agree that equity of access is crucially important but disagree with the implied definition of what a good death is.

The authors imply that a good death is one that is pain free, dignified, and one in which active resuscitation never occurs. If this is what the patient has requested, either verbally or through an advance directive, then this would be appropriate. However, we think that death can at times be unfair and premature and that a calm good death may not be what such a patient wishes. Such patients may wish to “rage against the dying of the light”;<sup>2</sup> may never accept their end calmly, and may not wish to be pain free. The concept of a patient not wishing to be pain free and peaceful is so far removed from our concept of good that professionals may consider such a patient to be non-rational.

We argue therefore that to force patients to have what we would call a good death is inherently medically paternalistic. A good death is one that is appropriate and requested for by that particular patient. Our duty as healthcare professionals is to ensure that resources and skills are available for their, not our, good death to occur.

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### Each encounter with a dying patient is a unique privilege

EDITOR—I think that Rabbi Julia Neuberger may be wrong when she says that nothing can prepare a young doctor, nurse, or rabbi for facing people whose death is imminent.<sup>1</sup> My experience shows quite the opposite. My

work to date has been blessed by the company of pastoral and clinical carers who are passionate about the journey towards death and who, together with eloquent and articulate next of kin, have been only too keen to share their wisdom and experiences, both good and bad.

Perhaps it is more accurate to say that each and every encounter with a dying patient and their family is unique and, however competent we become, we can always learn and—if we are especially privileged—share.

If young professionals choose to shy away from sharing the journey then perhaps that says more about the way we are choosing and training the newer generations than it does about the art of pastoral and clinical care.

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### Spiritual care is important for a good death

EDITOR—The 12 principles of a good death were built on in the article by Ellershaw and Ward.<sup>1</sup> I am a hospital chaplain, and religious and spiritual care therefore has a particular resonance.

Although religion and spirituality are important for all patients, they can take on extra importance as death approaches, allowing members of the team to broach topics that are often considered taboo. Would patients like particular preparations to be made for their death, perhaps to make peace with their family or Maker? Would they like to discuss funeral arrangements? Do they have any dying wish that it is possible to fulfil?

These are delicate issues, and it is encouraging to believe that a time is coming when we diagnose a patient as dying in a hospital as readily as we do in a hospice. Pastoral doors can be opened and bridges built between the team, the family, and the patient.

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### Spiritual care of dying patients needs to be well prepared

EDITOR—We were glad that Ellershaw and Ward emphasised the importance of spiritual care in assuring a good death—an area of care that, we believe, is usually overlooked.<sup>1</sup>

The results of our local survey of the views of elderly patients with mental health problems and their carers on spiritual care were in keeping with the above idea.



Native Death Dance, Alice Springs, circa 1920, photo by Sir John Newlands

Moreover, they indicated that this type of care should be considered and provided sooner rather than later. Unlike physical care, spiritual care needs a lot of preparatory work for proper assessment and for the relevant needs to be tailored to suit individual patients in the context of their religious and cultural background.

Patients emphasised that spiritual care becomes more relevant as one approaches the end. One patient said: “As you are approaching death, you need to know that you are going to the right place.” One of the common themes was the importance of offering this type of care to all elderly patients but never to impose it.

Training needs were addressed, although poorly defined. We think that building some form of basic skills and knowledge for all professionals in this field, along with developing a specialised area for interested staff, might be the way forward.

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### A good death and medicalisation need not be polarised

EDITOR—Clarke warns against the medicalisation of dying when medicine and technology overstep the boundaries of the body or when palliative care focuses on symptom management.<sup>1</sup> This can be a reality but depends on the healthcare provider, such as when death is resisted—when it is inevitable or when technology is lengthening the dying process as opposed to providing a good death.

Healthcare providers need to be cognisant of the importance of caring for the body holistically, and not just focusing on the corporeal needs. Symptom management is an essential part of palliative care, but the heart of palliative care is the dying person.

Innovations have greatly affected the dying process—providing the dying person

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*The Death of Socrates* by Jacques-Louis David, 1787

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with options and control. Nevertheless, healthcare providers do impart a technological realism. They are the experts on medicine and technology, playing a key part in how patients perceive and embody technology. In addition, to what extent a dying person embodies the technology is unique and remains a comparatively uncharted matter.

Clarke notes that palliative medicine “lacks a specific disease, bodily organ, or life stage to call its own.” On the contrary, palliative medicine embraces Clarke’s quotation. The beauty of palliative care is that it does not marginalise a disease or life stage but embodies any dying person with any disease at any life stage.

To find a balance between humanism and technology, healthcare providers need to embrace the theory of patient centred care. Then technology will inadvertently and fortunately slide into the background. The positive or negative outcome of the medicalisation of the dying process is unique and contingent on not only the dying person but also the healthcare provider. Medicalisation and technology do not have to be polarised against a good death but can enhance the dying process in the interests of the patient.

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### Good death is achievable if task becomes easing death, not prolonging life

EDITOR—Death is almost inevitably medicalised in our society, and this leads to an increasing number of requests from professionals for ethical advice and from the public for an understanding of what is

permissible. British and Commonwealth law consistently enshrines all the necessary permissions for doctors to cease intrusive and life prolonging treatment when they consider that the treatment is of no substantial benefit to their patient.

Substantial benefit is best thought of as an outcome that the patient would regard as worthwhile now or in the future. Making such a judgment call mitigates the inordinate continuation of lifesaving measures such as respiratory and nutritional support. Any such intervention can be used only when clinicians judge that it will produce such a benefit and when the patient would be presumed, were he or she to be asked, to consent to the treatment. Both presumptions fail in many of the patients submitted to inappropriate rescue or lifesaving interventions, often resulting in an extended and poorly managed dying process.

If doctors are attentive to these considerations and to the clinical indicators of dying, they can straightforwardly move into a palliative mode and use whatever drugs are needed to keep the patient comfortable, despite any risks of the drugs in relation to vital functions. All Commonwealth countries allow this course of management under some form of the doctrine of double effect, in which the palliative treatments are used with the intent of alleviating suffering regardless of their side effects.

In this mode of care doctors can also be open with both patients and their relatives and remain with them rather than abandoning them to substandard care. When they understand that their task here is to ease the patient’s dying rather than strive for life at all costs, good deaths can become much more the rule than the exception in hospitals.

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### Human Rights Act 1998 imposes an obligation to facilitate a good death

EDITOR—Ellershaw and Ward argue eloquently for the compassionate care of dying patients.<sup>1</sup> We believe that the Human Rights Act 1998 (“the act”) may impose a positive obligation on NHS providers to facilitate a good death.

The act effectively incorporates the articles of the European Convention of Human Rights into domestic legislation. Article 3 provides for freedom from degrading treatment. A common misconception is that life preserving treatment must be provided to dying patients, even against clinical judgment, to avoid litigation. However, the futile continuation of invasive procedures and treatments may arguably amount to degrading treatment and a breach of article 3.

Although article 2 provides for the right to life, no positive obligation is imposed on the state to provide medical treatment if such treatment is bound to be ineffective. Recent case law illustrates this. Two applicant trusts applied for a declaration that it would be lawful to discontinue artificial nutrition in respect of patients in a permanent vegetative state.<sup>2</sup> The court concluded that the withdrawal of such treatment was lawful and in the best interests of the patients. However, the continuation of palliative care would be appropriate and humane. Active therapeutic interventions may be stopped when the medical prognosis is futile, thereby allowing patients to die with dignity.

Section 6 of the act states that it is unlawful for a “public authority” to act in a way that is incompatible with the convention rights. The NHS, its institutions, and its servants amount to a public authority. Trusts and their employees therefore need to be aware of their obligations under the act in respect of the care that they provide to dying patients. Healthcare professionals have a positive duty to ensure that the terminal care given allows death to occur with propriety and tranquillity.

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Competing interests: None declared.

1 Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life [with commentary by J Neuberger]. *BMJ* 2003;326:30-4.

2 NHS Trust A v M, NHS Trust B v H [2001] Fam 348

### Law needs to be changed to allow terminally ill people choice of a dignified death

EDITOR—I am a 35 year old married mother who has tested positive for the gene for Huntington’s disease. Although I am symptom free at present, it is clinically certain that this incurable, degenerative, neurological disorder will manifest itself at some point in the near future. Growing up in a family with Huntington’s disease means that I have an accurate picture of what is to come from personal experience. This is not only for the daily reality of the symptoms but also for death.

My maternal grandmother in her last few months was bedridden, doubly incontinent, incoherent, skeletal, and fed by tube and drip. Huntington's disease had caused her to lose control of her muscles, which meant that she had an extremely distressing death caused by choking on her own saliva.

When facing and dealing with terminal illness for which there is only one outcome then how that outcome happens becomes of huge importance. I want an open and honest relationship with my medical care team. At a time when I need their help most they are unable to help me under the existing law.

The law needs to be changed to allow me and the thousands of terminally ill people in the United Kingdom the choice of a dignified death if that is what we want. The Patient Assisted Dying Bill, currently in the House of Lords, would provide a transparent, patient driven framework to protect the medical profession and respect the choices of terminally ill people.

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Competing interests: None declared.

### Do we really know what happens in this country?

**EDITOR**—Rather than dwell on shortcomings in medical practice or the law on assisted suicide in Switzerland, the Netherlands or elsewhere, doctors in England, not just Gardner,<sup>1</sup> would help their patients more by asking what happens in the United Kingdom and why some terminally ill patients choose to end their lives in far from ideal circumstances in Zurich.

Gardner's objection to assisted dying lying alongside palliative care relies on the unproved assumption that if people knew enough about symptom management, there would be no call for it.

Expectations of palliative care are very high, as are the claims of its practitioners, but it cannot control everything even in terminal malignancy. It is debatable whether hospices have deliberately sequestered these aspects of dying within their walls, or whether a dying-denying public has chosen not to know or inquire about these aspects of dying with their accompanying losses of dignity and selfhood.<sup>3</sup>

A robust moral framework, which dictates how a sentient rational adult should think, let alone face incurable illness, has ominous connotations for what most of us believe is a free society.

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Competing interests: None declared.

1 Gardner G. Assisted suicide and euthanasia in Switzerland. *BMJ* 2003;327:52. (5 July).  
2 Smith R. A good death. *BMJ* 2000;320:129-30.  
3 Kite S. Upstream from death. *J R Soc Med* 2002;95:529-30.

### Both how and when determines a good death

**EDITOR**—Plutarch reports that when Julius Caesar was asked at a party with his friends what kind of death was the best, Caesar replied: "The kind that comes unexpectedly."<sup>1</sup> His wish was fulfilled. When we are young and healthy we do not like to think about the way we will die as death is a negative thought and is subconsciously pushed out of our mind.

Not being a burden (physically, mentally, and financially) to our loved ones at the time of death is a good way to die. Being physically and mentally completely independent almost to the time of death could be a wish only a few can hope to achieve. A non-lingering and quick death is a good death. Others would certainly applaud it for having saved them from experiencing the prolonged mental trauma of the inevitable death of someone they loved, liked, or revered.

Not only how one dies but also when one dies is important. People would like to see certain tasks completed before leaving this world for good. Of course this varies according to the person's cultural and religious background. In Hindu mythology the Mahabharata, the grandsire Bhishma had a boon of dying only when he wished. This is not the same as the modern day concept of euthanasia of ending your life voluntarily. Bhishma could postpone his death indefinitely. Wounded by the arrows of his grandnephews in the Mahabharata battle he lay there until the sun turned northward.

Even today, upper caste Hindus believe dying in the months when the sun is moving from south to north is an auspicious death. Similarly, every person would like to see certain life events in their family happening before his or her death, which is psychologically fulfilling to the dying person as well as helpful to the living ones to cope with the loss of the loved one. Certainly this acts as psychotherapy in certain cultures.

Both how and when death occurs make a good death.

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Competing interests: None declared.

1 Plutarch. *Fall of the Roman republic*. Revised ed. Harmondsworth: Penguin, 1972:303.

### A good death described

**EDITOR**—I like to think that my husband had a good death. He had cancer of the oesophagus, which was treated with chemotherapy and surgery. After that he had a good year but suddenly experienced breathing difficulty. He was admitted to hospital and told, very gently, that the cancer had spread.

He had expert help to ease his breathing and good pain control. He died a week later with his wife and children round him, without distress and (I think) without fear. He had had time to say the things he needed to say, and we had had time to do the same.

I am reminded of a quote from Morris West's *The Devil's Advocate*.<sup>1</sup> The hero priest says to the bishop, "I am dying my lord." The bishop replies, "As a man should, my son. With dignity and among friends."

I hope that I am so lucky.

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Competing interests: None declared.

1 West M. *The devil's advocate*. London: Heinemann, 1959.

## Adrenaline and non-life threatening allergic reactions

### Intramuscular adrenaline is safe

**EDITOR**—The life saving effects of adrenaline in severe allergic reactions are well established, so Johnston et al's lesson of the week cautioning against using adrenaline in "non-life threatening" conditions is worrying.<sup>1,2</sup> Anaphylaxis or angioedema of the upper airway is life threatening, and avoiding or delaying appropriate treatment is clearly associated with adverse outcomes, including death.<sup>3</sup>

We question Johnston et al's interpretation of their two case reports.

In the first case the association between the episode of angina and the administration of adrenaline is not clear, especially given the patient's established heart disease. Moreover, in acute settings angioedema affecting the tongue may not be easily discerned as benign. In this case regular antihistamines are clearly indicated as long term treatment rather than episodic adrenaline, which still might provide effective emergency treatment.

The second case should not be used as evidence. To caution against safe, lifesaving treatment on the basis of the adverse effects of an incorrect dose of drug given through an incorrect route at an inappropriate dilution is inappropriate. Adverse effects from the use of undiluted (1:1000) adrenaline administered intravenously are well described in the literature and in clinical practice guidelines. Doctors choosing the intravenous route for adrenaline administration should be aware of this.<sup>4,5</sup>

Conversely, intramuscular adrenaline (1:1000) in doses of 0.01 mg/kg to a maximum of 0.4 mg is well established as safe, even in cases without anaphylaxis, and is not associated, to our knowledge, with cardiac toxicity. Practitioners specialising in the treatment of allergic conditions should be clearly stating the dangers of intravenous adrenaline while safeguarding effective treatment in patients with life threatening allergic reactions.

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Competing interests: None declared.

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### Cause of reactions should be identified

EDITOR—Anaphylaxis, though rarely fatal, as pointed out by Johnston et al,<sup>1</sup> may happen when least expected. Johnston et al warned about the misuse of adrenaline, but they should also have emphasised the importance of trying to identify the cause of any anaphylactic or anaphylactoid (non-IgE-mediated) or even minor allergic reactions (urticaria and non life threatening angioedema).

Prevention is the best treatment: avoidance for foods and drugs, immunotherapy for insect bites. It is every allergist's experience that a minor reaction today does not necessarily mean a minor reaction tomorrow. Before withdrawing an EpiPen, particularly in children and adolescents, every attempt should be made positively to identify the aetiology of the reaction. Careful history taking with attention to timing of the reaction, allergy skin or laboratory tests, evaluation of C1 inhibitor deficiency, and double blind, placebo controlled food challenges are all available tools for this purpose.

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Competing interests: None declared.

- Johnston SL, Unsworth J, Gompels MM. Adrenaline given outside the context of life threatening allergic reactions. *BMJ* 2003;326:589-90. (15 March.)

### Authors' reply

EDITOR—We agree that adrenaline can be life saving in severe allergic reactions. In our lesson of the week we carefully stated that using adrenaline as firstline treatment in true systemic anaphylaxis is not disputed.

We also agree that identifying allergens and subsequently avoiding them are key issues in managing allergy. The incidence of life threatening anaphylaxis is, however, influenced by allergen exposure rather than adrenaline use, and we support the use of adrenaline in this context.

The message we want to convey is that adrenaline can be life saving in true systemic anaphylaxis but can be hazardous when used out of context. Correct management of localised angioedema not affecting the larynx and without hypotension or bronchospasm includes antihistamines and steroids, with careful observation for the development of systemic features, which

require adrenaline. Indiscriminate use of adrenaline for non-life threatening features in patients with contraindications to treatment with adrenaline has to be questioned.

The medical emergency in case 1 was a result of adrenaline (precipitation of angina) rather than localised angioedema. Adrenaline is not a recognised treatment for urticaria and facial angioedema in the absence of systemic features. Intravenous adrenaline should be reserved for patients with immediately life threatening profound shock where appropriate monitoring facilities exist. Case 2 therefore had a life threatening complication from unnecessary adrenaline.

Both cases highlight the importance of appropriate education for and supervision of medical staff. In a study of senior house officers at the start of their accident and emergency post, 10-56% would be prepared to administer adrenaline inappropriately.<sup>1</sup> The series of deaths reported by Pumphrey support our concerns.<sup>2</sup>

We have advised withdrawal of EpiPens only when a diagnosis of acute systemic anaphylaxis could not be substantiated and adrenaline had caused dangerous side effects.

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- Gompels LL, Bethune C, Johnston SL, Gompels MM. Proposed use of adrenaline (epinephrine) in anaphylaxis and related conditions: a study of senior house officers starting accident and emergency posts. *Postgrad Med J* 2002;78:416-18.
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### BMA secretary responds to news story

EDITOR—That your news story about the way in which I responded to a motion about staff pay at the BMA's Torquay annual representative meeting presents a partial view of the episode is not surprising.<sup>1</sup> I was given no opportunity to explain myself at the meeting; neither did your correspondent feel it necessary to talk to me before going into print.

What on earth, your readers and BMA members may ask, was the BMA secretary doing deploying legal threats to suppress legitimate debate when everyone else was having such a good time at the seaside? Who does he think he is?

Let us be clear: the motion was not merely directed at me personally and couched in offensive terms, but, in implying that I had been in serious breach of my duties, it was demonstrably false and thus defamatory. These are harsh, but entirely apt, words.

I expressed this view to Dr George Rae, chairman of the representative body, and also suggested to him that were the motion to be debated he might like to remind any participant who contributed in false and disparaging terms that I would take any necessary action to defend my reputation. So while I had no intention of allowing myself to be publicly traduced (I am a member of another learned profession and the annual representative meeting is open to the media), it is a serious misrepresentation—not to use a harsher term—to report, as you did, that I “threatened to sue the chairman of the representative body.”

Asked by the agenda committee on the morning of the debate what outcome I wanted, I said that I would like the motion to be withdrawn. I emphasised that I had no problem with a discussion about the merits of the underlying issue, which is whether BMA staff should continue to have their salary increases automatically linked to rises in general practitioners' pay. The committee responded that it could not withdraw the motion at that stage but explained how it would seek to manage and defuse the situation should there be a debate. A sort of understanding was reached at this time: an understanding with which the subsequent surprise contribution from the podium of the agenda committee member which you reported, and in which he purported to give a statement of the facts, was entirely inconsistent. Neither Dr Rae, for whom I have the highest regard, nor his deputy, Dr Michael Wilks, was aware of what their fellow committee member was going to say. Neither of course was I.

One final point. When the chairman of the Eastern Region Junior Doctors Committee (which had proposed the offending motion) was approached on the morning before the motion was due to be debated, he wrote immediately that he was more than happy to withdraw it and pointed out that the motion had also been withdrawn from the JDC conference as he “felt it was inappropriate and therefore not suitable for proposal.” He did “not know how it could have reached the ARM under these circumstances.” I don't remember anyone passing this information on to the meeting in Torquay.

It's a funny old world.

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Competing interests: See text of letter.

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